

DOCUMENT RESUME

ED 463 440

CE 083 115

TITLE The Captain's Log. Canadian Conference on Literacy and Health: Charting the Course for Literacy and Health in the New Millennium. (1st, Ottawa, Ontario, May 28-30, 2000). Final Report.

INSTITUTION Canadian Public Health Association, Ottawa (Ontario).

SPONS AGENCY National Literacy Secretariat, Ottawa (Ontario).

ISBN ISBN-1-894324-15-3

PUB DATE 2001-01-00

NOTE 69p.; Published by the National Literacy and Health Program.

AVAILABLE FROM For full text (in English or French):
<http://www.nlhp.cpha.ca/conference/>.

PUB TYPE Collected Works - Proceedings (021) -- Reports - Descriptive (141)

EDRS PRICE EDRS Price MF01 Plus Postage. PC Not Available from EDRS.

DESCRIPTORS Adult Basic Education; Adult Educators; *Adult Literacy; Allied Health Occupations; Communication Skills; Conferences; Cooperative Planning; Cultural Differences; Disabilities; Educational Planning; Educational Practices; Educational Resources; Foreign Countries; *Functional Literacy; *Health Education; *Health Promotion; Indigenous Populations; Information Dissemination; Instructional Materials; Internet; *Literacy Education; Material Development; *Partnerships in Education; Research Methodology; Resource Materials; Teacher Student Relationship; Training; Trend Analysis; World Wide Web

IDENTIFIERS *Canada; United States

ABSTRACT

This document presents materials about and from a conference on literacy and health that was held to examine the connections between literacy and health and to provide Canadian health professionals, government representatives, literacy providers, adult learners from Canada and the United States, and other participants with practical skills and hands-on learning opportunities that could be useful in their work. The document is divided into 5 sections devoted to the following themes that served as the basis of the conference's 37 workshops and 2 sub-plenaries: (1) making health services and health information easy to use for all Canadians; (2) looking for ways to improve the training of health professionals; (3) learning more through research; (4) learning from learners; and (5) building literacy and health partnerships. Each section contains some or all of the following elements: an overview; discussions of specific issues; case studies; success stories; pertinent quotations; recommendations; and references. The following are among the specific topics discussed: (1) improving access to health services and health information; (2) identifying and helping low-literacy patients; (3) communicating clearly; (4) understanding the barriers caused by cultural differences and disabilities; and (5) research and policy trends in Canada. Lists of conference presenters and 15 World Wide Web sites are appended. (MN)

The Captain's Log

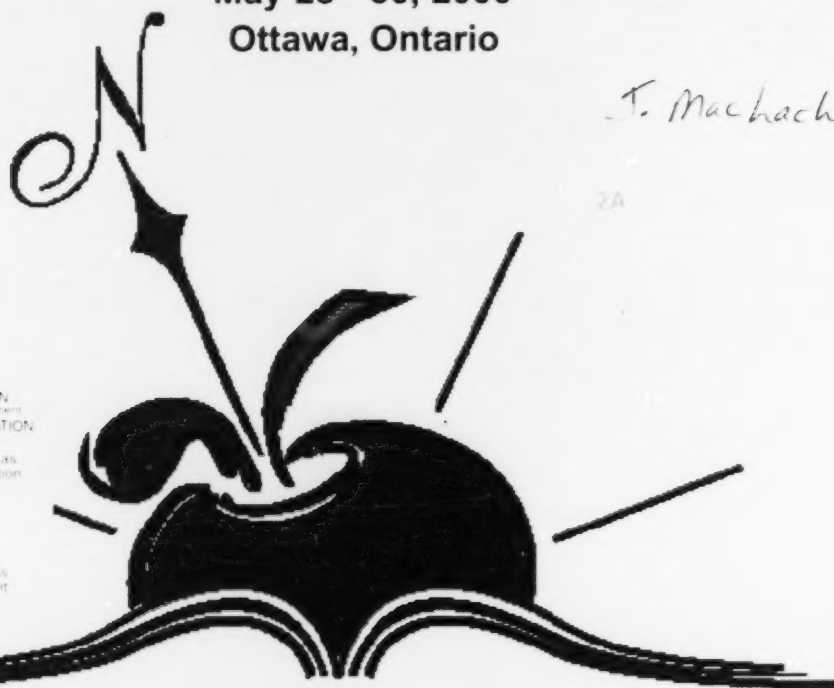
First Canadian Conference on Literacy and Health

**Charting the Course for
Literacy and Health in the New Millennium**

**May 28 - 30, 2000
Ottawa, Ontario**

J. MacEachlan

2A



U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION
CENTER (ERIC)

☒ This document has been reproduced as
received from the person or organization
originating it.

☐ Minor changes have been made to
improve reproduction quality.

• Points of view or opinions stated in this
document do not necessarily represent
official OERI position or policy.



Canadian Public Health Association



National Literacy and Health Program

Funded by the National Literacy Secretariat

2

**Final Report
January 2001**

BEST COPY AVAILABLE

CE083115

The Captain's Log

First Canadian Conference on Literacy and Health

Charting the Course for Literacy and Health in the New Millennium, May 28-30, 2000

Final Report, January 2001

ISBN: 1-894324-15-3

Copyright © 2001, Canadian Public Health Association.

Permission granted for non-commercial reproduction only.

For more information contact:

Canadian Public Health Association

400-1565 Carling Avenue, Ottawa, Ontario K1Z 8R1

Tel: (613) 725-3769

Fax: (613) 725-9826

Email: comm@cpha.ca

Internet: www.cpha.ca

Aussi disponible en français.

This publication is also available on the Internet at the following address:

www.nllhp.cpha.ca

The Captain's Log

First Canadian Conference on Literacy and Health

***Charting the Course for
Literacy and Health in the New Millennium***

**May 28 - 30, 2000
Ottawa, Ontario**

**Final Report
January 2001**

Acknowledgements

The Canadian Public Health Association's (CPHA) National Literacy and Health Program would like to thank:

- The National Literacy Secretariat for providing the major funding for the conference.
- The Conference sponsors who also made generous contributions: Health Canada, Pfizer Canada Inc., Pfizer Inc, Canada's Research-Based Pharmaceutical Companies, Hoffmann-La Roche Ltd., The Canadian Medical Association, Glaxo Wellcome Inc., and AutoSkill International Inc.
- The Scientific Program Committee members: Rosemary Killeen, Judy King, Jay Lynch, Dianne Kinnon and Arlene MacLowick.
- The speakers, theme chairs, moderators, sub-plenary presenters, workshop presenters and workshop chairs for their expertise, dedication and enthusiasm.
- The Weiler Award Trust Fund for designating the 2000 Weiler Award to honour an individual or organization who or which has made a substantial contribution to the literacy and health field in Canada.
- The National Literacy and Health Program partners who offered their expertise and guidance and generously publicized the conference to their respective memberships.
- The many literacy organizations for their assistance in promoting the conference within the literacy communities.
- The adult learners from Canada and the United States for their participation at the conference as delegates and presenters and for their contributions to the Learners' Wall.
- The conference delegates who came from Canada, the United States and overseas to participate in this first Canadian conference on literacy and health.

Table of Contents

Introduction	1
Theme 1 Making health services and health information easy to use for all Canadians.....	8
Theme 2 Looking for ways to improve the training of health professionals	16
Theme 3 Learning more through research.....	29
Theme 4 Learning from learners.....	38
Theme 5 Building literacy and health partnerships.....	46
Conclusion	52
Appendix 1 List of Conference Presenters.....	55
Appendix 2 Resources.....	61

Introduction

In partnership with 26 national health associations, the Canadian Public Health Association raises awareness about the links between literacy and health among health professionals. Specifically, over the past nine years, CPHA's National Literacy and Health Program (NLHP) has promoted plain language health information and clear verbal communication in the health profession throughout Canada. The NLHP has undertaken numerous projects in the following areas:

- seniors' prescription medication use
- access to health services and health information
- poor health communication and its impact on patients' informed consent and health professional liability
- hard-to-use forms that undermine the independence and well-being of low-literacy health consumers
- health among low-literacy youth

Over the past nine years, the field of literacy and health has grown tremendously. Numerous provincial and local health and literacy organizations have joined forces with the NLHP and its partners. As a result, health professionals and administrators are becoming more aware of the need for clear communication. For instance, health professionals are using the NLHP resources to help them improve health communications in their practices. They are also exploring ways to make their facilities more friendly to people with low literacy.

At the same time, more and more academics in both the health and literacy fields are approaching the NLHP for support. They want to do research in a variety of areas related to literacy and health. These areas include the impact of low literacy on health and other factors such as income and gender.

Finally, the NLHP continues to work with national literacy organizations to expand its relationships with learners. Over the years, adult learners have helped the NLHP to "translate" health material into plain language. They have also taken part in "focus tests" to ensure the material is appropriate for low-literacy health consumers.

Quote

"I cannot and will not turn away from an issue which finds more than 40 percent of Canada's adult citizens in varying degrees of difficulty every day of their lives because of inadequate reading, writing and numeracy skills, which we take for granted."

Senator Joyce Fairbairn,
P.C.

Learners and literacy providers have encouraged CPHA to continue its work with health providers. In fact, many have told us that it is just as important to teach communication skills to health professionals as it is to teach literacy skills to learners.

In 1997, through its many partnerships and networks, the NLHP learned about a strong desire among diverse sectors to boost the profile of literacy as a health issue. These sectors ranged from health professionals and administrators, to researchers and academics, to adult learners and literacy providers. In addition, these literacy and health advocates wanted to build and strengthen partnerships that would support their field work, now and in the future.

In response to this sweeping call for action, the NLHP proposed a national conference to address the connections between literacy and health. The focus of this conference would be to provide participants with practical skills and hands-on learning opportunities that could be useful in their work. In January 1999, with funding from the National Literacy Secretariat and several generous sponsors (see page ii), the NLHP and CPHA's Conference Department began planning the first Canadian conference on literacy and health. The conference, *Charting the Course for Literacy and Health in the New Millennium*, took place on May 28-30, 2000 at the Crowne Plaza Hotel in Ottawa, Ontario.

How the Conference was Organized

Early in the planning stages, the NLHP set up a committee to lay the scientific groundwork for the conference. The Scientific Program Committee was composed of two NLHP partners, a pharmacist and two consultants. One of the consultants had extensive experience in health promotion, including work with the NLHP. The other consultant had expertise in literacy and working with adult learners.

The Committee agreed that literacy and health was a new field, and that a broad-based conference could attract a wide range of stakeholders. Therefore, the committee organized the conference program around five broad themes revolving around literacy and health issues.

Five Themes

1. Making health services and health information easy to use for all Canadians
2. Looking for ways to improve the training of health professionals
3. Learning more through research
4. Learning from learners
5. Building literacy and health partnerships

Plenaries

The conference offered three plenaries, each of which had a specific purpose. The Opening Plenary, held the first evening of the conference, welcomed participants and set the tone by featuring three inspiring speeches:

- Dr. John Hastings, CPHA's Past President, eloquently situated literacy and health in a public health context.
- Senator Joyce Fairbairn, P.C., Special Advisor for Literacy to the Minister of Human Resources Development Canada, and a dedicated literacy advocate, urged participants to pursue their work in the field.
- Mrs. Dorothy Silver, an adult learner who is a spokesperson on the Board of Directors for the Movement for Canadian Literacy (MCL), gave a moving address. She talked about being an adult without literacy skills and how she struggled to navigate the health system throughout most of her life.

At the Working Plenary, held the first morning of the conference, three Theme Chairs gave an overview of each theme:

- Dr. Owen Hughes, a family physician with an active practice in Ottawa, discussed Themes 1 and 2.
- Dr. Rima E. Rudd, Director of Educational Programs at the Department of Health and Social Behavior, School of Public Health, Harvard University, presented Theme 3.
- Finally, Mr. John Daniel O'Leary, President of Frontier College, discussed Themes 4 and 5.

At the Closing Plenary, held on the last day, the three Theme Chairs summarized what we had learned at the conference on each of the five themes.

Mr. George Maher, from the Plain English Campaign in England, moderated the Working and Closing Plenaries.

Sub-plenaries and Workshops*

Two sub-plenaries were organized, based on the conference themes, to showcase important milestones and accomplishments in the field of literacy and health. These milestones included the Ontario Public Health Association's groundbreaking *Literacy and Health Project-Phase One - Making the World a Safer Place for People who Can't Read*. They also included Health Canada's Second Report on the Health of Canadians, *Toward a Healthy Future*, which was the first federal report that identified literacy as a factor affecting health.

The conference offered 37 workshops and 2 sub-plenaries based on the five themes. Some workshops were offered in French. All workshops were participatory and designed in one of four ways:

- Case studies
- Panel discussions
- Skills and training
- Dialogue sessions

The workshops covered a variety of topics, including the following:

- informed consent and health professional liability
- literacy testing
- pictograph health instructions
- organizational change for plain language
- Internet solutions for health consumers with low literacy

* *All workshops offered at the conference are described on the NLHP web site at www.nlhp.cpha.ca.*

- medication matters for seniors
- health communications for low-literacy deaf, hard-of-hearing and developmentally disabled people

Participants

Conference participants included the following:

- Health professionals
- Government representatives
- Researchers and academics
- Literacy providers
- Health administrators
- Policy makers
- Adult learners from both Canada and the United States
- Representatives of pharmaceutical companies

Exhibit Hall

Throughout the conference, participants had a chance to visit the Exhibit Hall. The Hall featured many colourful displays and offered important information on a variety of literacy and health-related topics and issues.

Learners' Wall

The conference was proud to display the Learners' Wall: a 10-foot high wall of learners' health stories from across the country. Mme. Luce Lapierre, Director of the Fédération canadienne pour l'alphabétisation en français, presided over the unveiling of the wall. Learners contributed their stories both before and during the conference. These stories provided conference participants with moving accounts of the struggles many adult learners face as they attempt to access vital health information and services.

Weiler Award

On the first day, the conference presented the Weiler Award. The fundamental theme of the Award is furthering social development and social justice through partnerships among individuals and organizations. The 2000 Award honoured an individual or organization who or which has made a substantial contribution to the literacy and health field in Canada, and who or which has furthered the use of plain language and clear verbal communication in Canadian health practice.

In 2000, there were two recipients.

The first Weiler Award was presented to Dr. William Hettenhausen, a dentist from Thunder Bay, Ontario. Dr. Hettenhausen has dedicated himself to developing and using plain language dental information in his practice.

The second Weiler Award was presented to The Centre for Literacy of Quebec. The Centre, located in Montreal, is committed to supporting and improving literacy practices in schools, community and workplace.

Sponsors

The National Literacy Secretariat provided major funding for the conference. The following sponsors also made generous contributions:

- Health Canada
- Pfizer Canada Inc.
- Pfizer Inc
- Canada's Research-Based Pharmaceutical Companies
- Hoffmann-La Roche Ltd.
- Canadian Medical Association
- Glaxo Wellcome Inc.
- AutoSkill International Inc.

How the Captain's Log is Organized

It was not possible to summarize each of the 37 workshops in the conference. Therefore, like the conference itself, the Captain's Log is organized around each of the five themes.

Each theme begins with an overview followed by various sections that look at specific issues. Wherever possible, we have provided sources for the information. This is usually a workshop or plenary from the conference itself. However, in some cases, we have provided additional information from published documents.

Each theme ends with recommendations presented at the Closing Plenary. (The three Theme Chairs reviewed all recommendations from the conference. At the Closing Plenary, they presented the main recommendations from each of the five themes.) Quotes from learners, case studies and success stories are scattered throughout the entire document.

The Captain's Log has been written using the principles of plain language and clear design. Please note that we have tried to respect the different terms used by each presenter. This may sometimes lead to inconsistencies. For instance, some use the term "learners" while others prefer "adult learners". Sometimes learners are referred to as low-literacy health consumers. Also, the terms "clients" and "patients" are used interchangeably.

We hope that you find the Captain's Log useful to your work.

Theme 1: *Making health services and health information easy to use for all Canadians***Overview**

Research is showing that people with low literacy skills face more barriers in the health system than other people. These barriers can be both visible and invisible. They mean that people with low literacy skills are more likely to have poor health than other Canadians. Seniors, people who live in the North, people who are poor, and people who are physically or mentally handicapped are especially vulnerable.

Health care providers need to help people with literacy problems to "navigate" the health system more easily. At the conference, health providers and learners came up with different ways to improve access.

The strategies, outlined in the pages that follow, include:

- **Build self-esteem from an early age**

Strong parenting skills can help children build the self-esteem they need to learn. It is also true that parents with low literacy may lack the skills to help their children read. Moreover, parents may go to great lengths to hide their literacy problem. The Literacy and Parenting Skills program in Calgary, Alberta has developed a program to address this challenge.

- **Use pictographs**

A pictograph is a drawing that represents an idea or an action. Pictographs can be very effective. However, for obvious reasons, they do not work well for people who are visually impaired. Pictographs must also reflect the cultural context in which they are used. An image that works in southern Ontario may not work in the North.

- **Make health environments more friendly and caring**

Medical institutions must change on several levels. Health professionals must become more sensitive to the needs of low-literacy patients. At the same time, the institutions themselves can adopt simple strategies such as "footsteps" that direct patients to the reception area.

- **Provide accurate and clear health information on the Internet**

The Internet presents both opportunities and challenges with respect to accessing information. On the one hand, it provides easy access to a wealth of material related to health. On the other hand, this information is not always reliable.

Build self-esteem

A child's path to literacy begins at home. Strong parenting skills can help children build the self-esteem that contributes to literacy. Parents – and all adults – can build their children's self-esteem in several ways: by showing interest in what children do, by encouraging them, and by listening to them.

Parents who lack literacy skills themselves face a greater challenge. Moreover, it can be difficult to attract adults to a "literacy" program since this draws attention to their problem. The Literacy and Parenting Skills (LAPS) program in Calgary, Alberta tries to attract low-literacy adults by talking to them about their children's literacy. This increases the comfort level and creates a non-threatening environment.

Use pictographs

Pictures are easier to remember than words. That is one reason why many people use pictures to tell stories. For example, some native cultures carve images on totem poles, and many religious groups paint pictures on the windows of their churches to tell a story. Bearskin Airlines uses pictographs to show people what to do in case of a problem with the airplane. The airline also includes written instructions in Aboriginal languages.

Tips for making pictographs¹

- Keep the drawings simple, both in terms of language and the ideas you are presenting.
- Avoid warm, fuzzy pictures to create atmosphere.
- Use drawings that show actions.
- Use photos if you need them (for example, to show a product).
- Use several pictures to create a story for complex content.

Quote

"As a physician, when a child comes to your office for a visit, try to remember to take five seconds to give that child a boost, not a booster, but a boost by saying something positive. It might be the only positive thing that child has heard that day."

Dorothy Silver,
Adult Learner

Quote

"I went to the clinic for a medical test, and I was put in a small room to watch a video which explained what was going to happen. I thought that was a very good idea."

The Learners' Wall

- Use simple, non-ethnic drawings.
- Use artists only after you know what you want to show.

Make health environments more friendly and caring

For many people – especially seniors – a visit to the hospital or the doctor's office can be a nightmare. People with low literacy skills often have trouble filling out complex forms. They have difficulty expressing themselves to impatient or insensitive nurses and doctors. As a result, they often do not understand the verbal or print health instructions they are given.

The conference looked at ways for doctors and nurses to make medical institutions more friendly and caring places. One way is to use plain language with all patients, both when speaking and writing. Another way is to identify patients with low literacy skills, and to provide information specially adapted to meet their needs.

It is not easy to identify someone with a literacy problem. Many adults are embarrassed by their lack of literacy skills. They will go to great lengths to hide the problem.

Two solutions were offered at the conference:

- find out the reading levels of patients
- create an environment in the hospital that is friendly to people with low literacy skills

Find out reading levels of patients²

It can be a challenge to find out a patient's reading level. Here is a list of things you should and should not do.

Do

- Ask general questions. For example: "Tell me how you will explain what you've learned to your family."
- Ask them to think about a time when they learned something new. Did they watch someone else do it? Did they read how to

do it? Did they watch it on a video? Ask them how they would like to learn today.

- Develop two versions of the printed material. One can be a basic version written at a Grade 4 to Grade 6 level. The other version can have more information. Offer both versions to the patient.

Do not

- Do not ask, "Do you understand?"
- Do not give patients something to read and then ask questions to see if they understand it.
- Do not hand patients something upside down and watch to see if they turn it right side up.

Create an environment that is friendly to people with low literacy skills

There is no one single way to make hospitals and clinics friendly for patients with low literacy skills. Here are a few tips:³

1. Make your service easy to find

- Provide landmarks and bus stop numbers when you give directions to your office.
- Create a sign or logo that shows what you do: i.e., a dentist could use a tooth or toothbrush as a symbol.
- Help clients find your office inside the building by placing symbols, i.e., footsteps or arrows from the entrance of the building to your door.

2. Reorganize your reception area

- Create a private place in the office where clients can fill out forms themselves or where someone can sit with them and help them fill out the forms.

Quote

"Once, before an operation, I was asked to fill out forms. One question asked about allergies. Well, I'm allergic to Demerol, but I didn't know how to write it, so I left it blank. After surgery they gave me Demerol and I threw up."

The Learners' Wall

Success story

The Hamilton Health Sciences Corporation is the largest provider of comprehensive health services in Ontario. For more than 10 years, the hospital's Patient Education Services has worked with medical staff to prepare education materials for patients. It believes that "providing" information is not the same thing as "making sure that people understand the information."

Patient Education Services uses a consultation model that encourages teamwork among patients and families, patient care experts and patient education specialists. It challenges assumptions and thinks about change in a comprehensive way. At the same time, it does not stick to rigid rules. By taking a flexible approach, Patient Education Services juggles the needs of all the people involved and their changing priorities.

3. Change your reception routine

- Use plain language forms.
- Offer to help clients fill out the necessary forms.

4. Help prepare clients for their treatment

- Provide easy-to-read or audio-visual materials that relate to your clients' treatment while they sit in the waiting room.

5. Talk with your clients and make sure they understand

- Avoid rushing through visits with your clients.
- To reinforce your message, give them easy-to-read health information and treatment plans at the end of their visit.

Get Institutions to change⁴

Change is a process, not a one-time event. Research has identified six steps that people go through to make a change. It involves pre-contemplation, preparation, contemplation, action, maintenance and termination.

Change does not move from "A" to "B". It is normal for people to "backslide" to old behaviour. In fact, it can take six months to a year before change is solid.

One study of an American farming community illustrates the process of change. The study found that 10% were "innovators," 10% were "early adapters," and 50 to 70% fell into a group that takes more time to adapt. Another 10 to 14% will simply not change.

In an organization, change creates many fears. These include fear of job loss, failure or loss of status. As a result, change takes a great deal of energy. It "shakes up the place."

Here are five steps to help promote change in a health institution:

Step 1 Determine the benefits

Use the economic benefits of plain language to get doctors on side.

Step 2 Get key players on board

Key players include deans of medicine, site committees, multidisciplinary committees and communications committees. You will need to sell the idea of a caring hospital setting to these players. For your sales pitch to work, these players must be "early adapters."

Step 3 Create a vision and a plan

Conference participants identified several ways that a vision and plan might help their organizations to change. First, it would create a space where patients could ask more questions. Doctors would have to adjust their ways of working. There would be a power shift. Second, it would create more choice for health care consumers by leading to a wider range of resource materials.

The plan would also recognize that plain language writing takes a lot of time and training. Humour can go a long way toward showing the needless complexity of government writing. For example, you could "translate" a three-minute speech full of jargon into a three-word statement.

Step 4 Communicate everything often

Communicate your message in creative ways – use everything from newsletters to bathroom signs.

Identify the communication challenges in your organization. Talk to opinion leaders. It is difficult to bring about change from the "bottom-up." Without support from senior management, real change is impossible. Timing is everything: know your limits and the economic context (if the economy is on a downslide, this may not be the time to push for plain language).

Step 5 Create success, advertise, adjust

Build on your successes. Tell people about them. Adjust your approach based on what you have learned.

Success story

The Montreal General Hospital believes in "patient education." Together with The Centre for Literacy, also located in Montreal, it is creating a Health Literacy Centre to provide culturally appropriate support for patients with low literacy, as well as for their families and caregivers. The Centre will also help health professionals develop the skills and tools to communicate with patients who have low literacy skills.

Provide accurate and clear health information on the Internet

The growth of the Internet has allowed people from all walks of life to access information from their homes and offices, as well as other sites such as public libraries.

By the end of 2000, 60% of Canadians used the Internet to find information on health. The quality of that information, however, did not always meet people's needs.⁵

People with low literacy tend to prefer the telephone over the Internet. Why? First, they may not have enough money to buy a computer and pay for a service provider. Second, they may not have the necessary literacy skills to find or understand information on the Internet.

The Information Highway holds great promise for providing information on health. However, it can also spread misinformation. The "language" of the Internet also creates a new level of literacy that people need to have.

Organizations have a responsibility to create web sites that are easy to use. They need to provide information in clear language and also use clear design principles. To that end, participants at the conference heard about two success stories:

The National Adult Literacy Database (NALD) (www.nald.ca), based in Fredericton, New Brunswick, provides the opportunity to literacy organizations in Canada to place on-line information about their projects and services. It also designs and mounts web sites for literacy organizations on its own site and registers them with search engines to ensure greater visibility of their message. In fact NALD worked closely with CPHA's NLHP to design and mount its web site, introducing the literacy and health issue to a much broader audience.

The Canadian Health Network (CHN) (www.canadian-health-network.ca) gathers Canadian resources on health issues. In its early stages, it chose organizations and individuals with expertise. This enabled CHN to build credibility right from the beginning. As one of its most innovative features, it has revised "Frequently Asked Questions" (FAQs) on a variety of health-related topics into plain language. More than 500 organizations have posted information on the site.

**References:**

1. Peter S. Houts. A Picture is Worth a Thousand Words – Using Pictographs to Help Patients Remember Important Instructions. (Workshop). Canadian Public Health Association, *First Canadian Conference on Literacy and Health*. Ottawa. May 2000.
2. Audrey Riffenburg. Does Literacy Testing Improve Health Delivery? (Workshop). Canadian Public Health Association, *First Canadian Conference on Literacy and Health*. Ottawa. May 2000.
3. Canadian Public Health Association. *Easy Does It! Plain Language and Clear Verbal Communication Training Manual*, Unit 6. Ottawa: CPHA. 1998.
4. Sue Stableford. Shock, Inspire, Support – Managing the Organizational Change to Plain Language. (Workshop). Canadian Public Health Association, *First Canadian Conference on Literacy and Health*. Ottawa. May 2000.
5. Oonagh Maley and Shawn Chirrey. Promoting Health Among At-risk Youth. (Workshop). Canadian Public Health Association, *First Canadian Conference on Literacy and Health*. Ottawa. May 2000.

Theme 2: *Looking for ways to improve the training of health professionals***Overview**

When people talk about the need for literacy training, they often think first about what learners need to do for themselves. However, there is also a pressing need to teach doctors, nurses and medical students about how to communicate more effectively with low-literacy health consumers.

There are two main ways to help low-literacy patients.

The first is to try to identify these patients and provide them with information that is specially adapted to their needs. Literacy tests have been developed to help the health provider find out if a patient will need special care. However, many critics claim these tests are, at best, impractical. At their worst, the tests can shame patients, and make them feel even more uncomfortable.

The second way to help low-literacy patients is to use simple and clear language, both verbal and written, with all patients. Plain language is crucial, especially with respect to consent forms. At the conference, participants explored several issues related to the plain language training of health providers, including the following:

- Clear verbal communication
- Shame-free communication
- Writing in plain language (especially consent forms)
- Understanding barriers caused by cultural differences and disabilities
- Assessing written materials
- Multi-media communication
- Introducing medical students to the needs of low-literacy patients

Clear Verbal Communication

Verbal communication includes facts, advice and "small talk." It also includes nonverbal cues and expressions such as nodding the head.

Clear verbal communication is a way of speaking that is easy to understand. For doctors, it means organizing what they say so that it is easy to remember, checking with clients to make sure they have understood and suggesting treatment plans that clients can actually follow. It also includes listening to patients and giving them the chance to express their feelings.¹

Some doctors are concerned about the extra time it takes to use clear verbal communication. However, in simulations, it only takes about 30 seconds longer to give extra explanations. That is a small investment considering it can save countless hours in repeat visits and telephone calls.

Tips for clear verbal communication

1. Organize your information.
2. Use common words, not technical jargon.
3. Give your clients a chance to express how they feel and to tell the story of their illness.
4. Make direct eye contact.
5. Use written information as a back-up.
6. Plan with your clients what they can do.
7. Let your client know what you are thinking.
8. Explain procedures and ask permission during examinations.
9. Focus on your client, not on notes, X-rays or the computer screen.
10. Check that your clients have understood what you have said.

Quote

"Think about your spoken language. If someone does not read well, they likely also have difficulty with medical terms. Talk to your patients using clear language. Ask your patients to repeat directions. Make sure they understand before they leave the office or emergency room visit. It may take one or two more minutes but it will save you time and expense later."

Dorothy Silver,
Adult Learner

Shame-Free Communication

People with low literacy often feel shame about their inability to read and write well. For instance, it is often difficult for learners to even admit they have a problem. Any action, even well-intentioned, that draws attention to their literacy problem can make them feel more shame. It may well push them further away from getting the help they need.

A shame-free communication approach means finding ways to interact with learners that treats them with respect and that encourages them to improve their skills.

The American Medical Association has produced a video called "Low Health Literacy: You Can't Tell by Looking." It shows people with low literacy skills talking about their negative experiences with doctors and hospitals. It also shows positive interactions between patients and health professionals: a nurse educator, for example, helps a learner understand a doctor's diagnosis.

The Bayer Institute for Health Care Communication is dedicated to enhancing health outcomes through improved clinician-patient communication. The Institute has developed a training program for doctors and faculty in medical schools. The program focuses on four "E" words:

- **Engagement** – this involves making person-to-person contact, asking about family or hobbies and taking the time to treat the patient like a person.
- **Empathy** – the patient must feel that he/she has been seen, heard and accepted.
- **Education** – this means providing information (verbal or written) in a way that the patient will understand.
- **Enlistment** -- this may involve the doctor saying to the patient at the end of the visit: "Do we have a deal that (you will take your medication, etc.)?" The doctor shakes hands before the visit ends.

Writing in Plain Language

Plain language is a way to organize and present information so that it is easy to read for the intended audience. When trying to reach a general audience, for example, you should write materials at a Grade 4-6 level so that the greatest number of people will get the message. See page 42 for tips on creating plain language texts.

Professional Liability and Patient Consent: Treatments and Operations

Health professionals have to inform their clients of the benefits, risks and alternatives of a medical treatment or procedure. If doctors fail to provide this information, the patient has the right to sue for negligence if something goes wrong with the operation or treatment. The breakdown in communication between patients and doctors is one of the main reasons for malpractice suits.

Before a treatment begins, a doctor should obtain "valid consent" from the patient. Canadian courts have identified several criteria² for valid consent:

1. The consent must be genuine and voluntary.
2. The procedure must not be illegal.
3. The consent must authorize the particular treatment or care, as well as the particular caregiver.
4. The client must have the legal capacity to consent.
5. The client must have the necessary mental competency to consent.
6. The client must be informed.

The last point is perhaps the most important. It is not enough for a patient to sign a "consent form". Several Canadian court decisions have suggested that informed consent is a process through which people receive information they can understand. They then use this information to help decide on a recommended treatment.

Professional Liability and Patient Consent: Clinical Trials

The issue of informed consent is even more crucial for people who volunteer to take part in clinical trials for new drugs or treatments. Since these participants are volunteers, they must be informed of the risks. However, a consent "form" for a clinical trial can often be up to 30 pages long. Even a person with a high level of literacy would find it difficult to understand such a lengthy form.

Here are several other considerations for consent forms that go beyond the issue of literacy:

- Cultural differences and disabilities may affect a person's ability to provide informed consent.
- Any patient can be anxious or frightened which can affect their ability to understand a consent form.
- Consent forms can be out-of-date and should be reviewed and updated every six months during ongoing trials.
- There are two types of risks, both of which should be explained clearly in the consent form or verbally to the patient: physical (harm to the body) and social (being labelled as someone with a problem if you take part in a study).

Components of informed consent³

- Purpose of the study
- Procedures and treatments
- Responsibilities
- Risks and benefits
- Confidentiality
- Voluntariness
- Time involvement
- Withdrawal consequences

Tips for designing consent forms

- Know the content, audience and goal of the study.
- Use clear design features like headers, 12- to 14-point type, 16- to 18-point bold type for headings, and split the page 50-50 between text and white space.
- Use clear, consistent language.
- Test for readability (remember that formulas do not address issues like format, layout, patient interest and motivation).
- Revise if necessary.
- Define technical words (for example, "nausea" = "sick to the stomach").

Understanding barriers caused by cultural differences and disabilities***Aboriginal cultures***

First Nations have the lowest health status in Canada. A variety of social/economic factors such as rampant unemployment, overcrowding, lack of educational opportunities, poor community infrastructure, environmental degradation and dietary changes contribute to a poor overall health picture regardless of where the First Nations citizen resides.

Traditionally, Aboriginal people lived by hunting and fishing in a highly sophisticated oral culture – a culture in which reading and writing were not necessary. The Cree and the Inuit, for example, did not have a written form of their languages until the mid-19th century. Today's Aboriginal people walk in two worlds: the traditional and the technological.

Parkland Regional College in Saskatchewan developed an approach to bridge these two worlds called "Reaching the Rainbow."⁴ In this approach, a colour code identifies the seven types of literacies needed by Aboriginal people (see next page). Whether the subject is technology literacy or spiritual literacy, the teaching must be culturally relevant to be successful.

Reaching the Rainbow:

- Red: Mother Tongue Literacy
- Orange: Oral Literacy
- Yellow: Literacy of Symbolism
- Green: English and/or French Literacy
- Blue: Literacy Using Technology
- Indigo: Spiritual Literacy
- Violet: Holistic Literacy

Ethnic and cultural groups

Ethnic and cultural groups face many barriers, including language and communication problems, beliefs and attitudes about health care and a lack of trust in the mainstream health care system.

Language

When a Chinese senior nods, it may mean that he or she understands you, agrees with you and will follow your advice. However, it may also mean that he or she thinks you are making a valid point, but does not agree with you.

Beliefs and attitudes

Many Chinese avoid hospitals because they are seen as places of bad luck.

Lack of trust

Certain elderly minorities (including those of African, Asian and Aboriginal descent) distrust the health care system because of past racism or society's mistreatment of their cultural group.

Unfortunately, many health care professionals and systems in Canada are ill-equipped and unprepared to break down these barriers.

Hearing impaired

Medical professionals often look at the deaf as people who cannot hear. Instead, they should realize that the deaf are people who simply understand the world in a visual way. At the same time, deaf people do not "see" the world in the same way as people who can hear. Deafness, therefore, should be considered as a "culture." Conference participants provided the following suggestions on how to improve communications between deaf patients and medical professionals.

Tips for better communication with the hearing impaired***Deaf patients***

- Bring along a sign language interpreter.
- Bring a list of questions for the doctor.

Medical professionals

- Remember deaf patients cannot hear their name over the PA system.
- Type out everything discussed with the patient in plain language.
- Take a basic signing course to establish some rapport.

Note: for tips on working with people who have developmental disabilities, see page 41.

Assessing written materials***SMOG Readability Formula***

CPHA's Plain Language Service uses the SMOG Readability Formula to assess the grade level of its written materials. SMOG involves taking groups of words from a text and then calculating the number of syllables using a simple formula.

Flesch-Kincaid Grade Level Index

The Flesch-Kincaid Grade Level Index is similar to SMOG except that your computer does all the work. Using Microsoft Word, you can automatically calculate grade levels on your documents. Under "Tools," choose "Spelling and Grammar." After Microsoft Word checks spelling and grammar, it will display "Readability Statistics," including the Flesch-Kincaid Grade Level Index.

SAM

The Suitable Assessment of Materials (SAM) is a system that rates the suitability of written materials. It looks at 22 factors that are broken down into six larger categories:

1. Content (amount of information)
2. Literacy Demand (readability)
3. Graphics (relevance of pictures)
4. Layout and Typography (clear design)
5. Learning Stimulation, Motivation (does the reader need to act?)
6. Cultural Appropriateness (age, race, gender)

The SAM system takes about 30 minutes to help you decide if your material is suitable for your target audience.

Learner Verification and Revision⁵

Another way to assess material is to invite learners to talk about their reactions.

The Process

1. Identify the key points in the material to be tested. The two or three most important points become the focus of your questions.
2. Write the questions to ask (no more than 10 questions). These questions focus on five specific elements:

Attraction	Is the instruction appealing to read or listen to? Is this something you would like to read?
Comprehension	Will the audience understand? Tell me in your own words what this is all about.
Self-efficacy	Will it stand alone? Do you feel you have enough information to carry out the instruction? If you do not, what are you missing?
Acceptability	Will the audience accept the information given in the pamphlet?
Persuasion	Will the pamphlet persuade the audience to change their behaviour?

3. Select a sample of patients to be tested.
You do not need a large sample of patients. Any major problem will appear in the first 10 responses.
4. Interview the patients.
Interview patients one-on-one for a few minutes (10 minutes maximum). Be sure to record everything that is said in the patient's own words. Do not paraphrase because you may lose important information.
5. Evaluate the patients' responses and revise material accordingly.
Watch for misunderstandings about behaviour and actions (such as following instructions about medication).

Multi-media communication

The success of communicating any message is knowing your audience, and developing materials that address and respect its needs. Multi-media messages can be very effective.

People remember:

- 10% of what they read
- 20% of what they hear
- 30% of what they see
- 70% of what they see AND hear

Steps to develop your message⁶**Get to know your audience:**

If you know your audience, you will be better able to decide what to include in the program. You can also make materials more culturally appropriate. And you can develop the best strategies to get the message across. You can learn more about your audience from the following:

- Community observation
- Meeting community leaders
- Informal conversations
- Surveys and in-depth interviews
- Focus groups
- Testing in the field

Look at these areas when designing your materials:

- Cultural health beliefs
- Treatments and remedies
- Potential gaps
- Preferred learning style of your audience
- Previous programs and approaches

Explore different types of visual materials:

- Posters and pop-ups
- Flip charts
- Table tents
- Talk boards

- Real objects and models
- Display boards
- Fotonovelas and brochures
- Audio-visual materials (audiotapes, videotapes, slide shows, CDROM)
- Multi-media (a combination of audio, video, graphics and text)

Introducing medical students to the needs of low-literacy patients

Research shows that effective health communication is not just a matter of personality. Rather, it is a learned skill. Educators have observed that providers who receive communication skills training enjoy more effective consultations with their patients. It leads to greater patient satisfaction and less misunderstanding. Effective communication is a basic clinical skill that demands as much attention as technical skills.

Problem-Based Learning (PBL)

Problem-Based Learning (PBL) helps medical students develop practical problem-solving skills. For instance, over two weeks, students might meet with a "standardized patient" – an actor who has been trained to play the role of a patient with a particular kind of illness. Students must diagnose the patient, provide rationale for their diagnosis and recommend treatment.

As part of the AMC Cancer Research Centre's PBL program, actor-patients provide cues that they have a literacy problem. These cues include the following:

- The health history form is filled out incompletely and inaccurately.
- The patient uses words inaccurately.
- The patient is confused by complex words.
- The patient tells related stories as part of answering medical questions.

The Captain's Log

- The patient folds up written information and puts it away.
- The patient asks for instructions to be repeated.

**References:**

1. CPHA. *Easy Does It!* Unit 3.
2. CPHA. *Easy Does It!* Unit 7.
3. Cathy Meade. Plain Language, Informed Consent and Health Professional Liability. (Workshop). Canadian Public Health Association, *First Canadian Conference on Literacy and Health*. Ottawa. May 2000.
4. Parkland Regional College. *Reaching the Rainbow: Aboriginal Literacy in Canada*. Yorkton, Saskatchewan: Parkland Regional College.
5. Cecilia Conrath Doak and Leonard G. Doak. Making Health Care Instructions Work! (Workshop). Canadian Public Health Association, *First Canadian Conference on Literacy and Health*. Ottawa. May 2000.
6. Jann A. Keenan. Health Resource Information – Professional Partnerships and Alternative Teaching Materials. (Workshop). Canadian Public Health Association, *First Canadian Conference on Literacy and Health*. Ottawa. May 2000.

Theme 3: *Learning more through research***Overview**

In recent years, studies in both Canada and the United States have confirmed that low literacy is widespread. Research also shows that low literacy has both direct and indirect impacts on health. People with higher literacy skills can stay in better health because they can understand and interpret health information. They may also be better able to prevent health problems and to detect problems earlier.¹

The reverse is also true. People with low literacy skills often feel alienated and have difficulty finding and accessing health information and services. As a result, they suffer poor health and die earlier than those who have higher literacy skills.

Research has also identified various kinds of "literacies." In fact, the definition of "functional literacy" is always changing. As society changes, people need to learn a new set of "literacies" that range from how to use debit cards at a banking machine to how to access information on the Internet.

While research has shown the direct and indirect impacts of literacy on health, income and other areas, there are still many issues to be explored. These issues include access to information, comprehension, learning styles and disabilities.²

Research and policy trends in Canada

Since the mid 1980s, many Canadian policy makers have recognized literacy as a serious issue. Below, we have highlighted important research and policy trends in Canada related to literacy.

In 1987, the Southam Survey revealed two important facts.

First, the survey showed that "functional literacy" was not about grade level. Rather it was about reading, writing and using numbers to meet the literacy demands of everyday society.

Second, it gave some indication of the problem. Partly because the survey left out northern communities and people in institutions and prisons, the results were very conservative. The survey found that 22-24% of adult Canadians needed help to meet their literacy needs (compared to 47% identified in today's research).³

In 1989, the Ontario Public Health Association and Frontier College identified major impacts of low literacy on health:

Direct impacts of low literacy

- older adults may not be able to use medication properly because they cannot read the label
- more visits to hospitals
- longer nursing home stays

Indirect impacts of low literacy

- poverty
- unhealthy lifestyle practices
- stress and low self-esteem
- dangerous work environments
- lack of or inappropriate use of health services

In 1990, Statistics Canada's National Literacy Survey showed that people with low literacy skills have more health problems. The survey results meant that health providers had an obligation to deal with the issue. It also meant that society could no longer blame people with low literacy skills for the problem.

In 1995, the International Adult Literacy Survey (IALS) explored three aspects of literacy: prose, document and numeracy. The survey concluded that 47% of adults have problems using the written word – these results were similar to the National Adult Literacy Survey carried out in the United States in 1992.

In 1999, the federal, provincial and territorial Ministers of Health released the public policy report *Toward a Healthy Future: Second Report on the Health of Canadians*. The report reflects a growing awareness that many factors affect "health," including genes, personal health practices, available health services, early child development, and social, economic and physical environments.⁴

The report identified the following literacy trends:

- Literacy levels are higher in the west and lower in the east.
- More males leave school early.
- Those aged 64 and over have lower literacy levels.
- The unemployed are three times more likely to have low literacy levels.
- People with low literacy levels feel alienated and have less access to health information and services and have poorer health.

The report recommended the following actions:

- Invest in the health of children, youth and Aboriginal people.
- Renew and reorient health services.
- Reduce the differences in income distribution, education and literacy across the country through these key strategies:
 1. increase employment opportunities and earning capacities for disadvantaged Canadians
 2. continue to use tax transfer and social policies to reduce inequities
 3. review the effectiveness of current programs that provide a safety net for Canadians
 4. support recreational and social services
 5. ensure that the essential needs of Canadians for food, shelter, privacy and security are met.

Quote

"People are unemployed, are poor, are addicted, are ripped off and are discriminated against because they can't read. People get in trouble with Revenue Canada, employment insurance and have a hard time filling out their health information forms or insurance forms because they can't read. People are in jail because they can't read. I know that people die because they can't read."

Dorothy Silver,
Adult Learner

The economic impact of low literacy

Statistics Canada's surveys on literacy have focused on the economic impact of low literacy. The final report from the International Adult Literacy Survey (IALS), released in June 2000, examined the relationship of literacy and income in 20 countries.

The report measured three types of literacy of adults aged 16 to 65:

- **Prose literacy** – understanding texts such as poems, news stories and fiction.
Canada ranked 5th out of 20 nations.
- **Document literacy** – using information in formats such as maps, payroll forms and bus schedules.
Canada ranked 8th out of 20 nations.
- **Quantitative literacy** – applying math skills such as balancing a cheque book.
Canada ranked 9th out of 20 nations.

Other highlights:

- Literacy has a major impact on earnings, especially when education and experience are also considered.
- 40% of Canadian adults were at the lowest two levels of literacy on all three literacy scales.
- 23% of Canadian adults were at the highest two levels on the "prose scale." Only Sweden had a higher rating at this level (32%).

Literacy, seniors and cardiovascular illness

Conference participants heard about a research project⁵ that is looking at the literacy needs of low-literacy seniors who are suffering from cardiovascular illness. The project is a partnership between the faculties of education and nursing at McGill University in Montreal and the University of Quebec in Quebec City.

The project has three phases:

Phase 1: Exploratory study

Phase 2: Development of education tools

Phase 3: Validation of tools and strategies

Researchers presented results of the project's first phase, which included the following:

Problem

Low-literate seniors with cardiovascular illness do not follow diets recommended by health professionals. They also do not take their medication as prescribed. Generally, seniors, especially low-literate seniors, are reluctant to change their habits.

Solution

Health care information must be adapted so that low-literate seniors understand their illness and take the necessary steps to recovery.

Focus groups with seniors revealed the following facts:

- Seniors looked positively on health care professionals who used plain language to help explain an illness.
- Seniors understood explanations when the words had meaning to them (e.g., when talking about diets, use "cups" and "tablespoons" rather than "portions").
- Seniors need time to think about how to phrase their questions. This is not due to poor memories. Rather, they need time to reconstruct and recollect information.

Research and policy trends in the United States⁶

Research into health and literacy in the United States has provided data about:

- the limited literacy skills of many American adults
- the high reading demands of most health information
- the poor health outcomes and system costs associated with limited literacy skills

The 1992 National Adult Literacy Survey (NALS) proved that almost half of American adults (90 million people) had only basic reading and math skills. It identified four groups with particularly limited skills:

- seniors
- recipients of public assistance

Case Study

A 1995 study of 3,000 emergency room and chronic care patients in Atlanta and Los Angeles revealed a clear link between literacy and health. Patients had trouble with verbal as well as written communications. Fewer than 40% with low literacy knew the name or purpose of their medications compared to more than 60% with higher rates of literacy.¹

- people of colour/ethnic minorities
- people with disabilities

Research has also identified several types of literacy.

"Documentation literacy," for example, is the ability to understand and fill out information on forms. "Quantitative literacy" is the ability to do simple math such as calculating a tip for a waiter at a restaurant. Since "functional literacy" relates to the society in which we live, it changes with the times. In earlier generations, a person could "get by" with a lower degree of literacy than today.

Collaborative research has brought greater attention to health literacy from the federal government and the medical profession. In 1998, the Clinton Administration mandated federal agencies to use plain language in their dealings with the public. And in 1999, the *Journal of the American Medical Association* recognized that health literacy is critically important to health care delivery.

Although policy makers are more aware of the literacy problem, there is no national health and literacy program in the United States. Health professionals concerned about literacy are scattered throughout the country and lack a "single voice" to push the agenda forward. Finally, few people recognize the social and economic impact of "limited health literacy."

Advocates have identified the need for the following:

- National-level public leadership (an American version of NLHP) that will "own" the issue and move the agenda forward.
- A national program that links major health, medical and literacy organizations.
- More policy development.
- More action-oriented research.
- More training for health, medical and literacy professionals.
- Funding to support these efforts.

A framework for understanding literacy

At the conference, a framework on health literacy⁷ was presented that pointed out that health literacy is distinct but that it relates to general literacy (see below). Other literacies such as politics and economics are also important.

General literacy

- reading ability
- numeracy
- judgement
- critical thinking
- interpretation of evidence
- communication and negotiation skills

Health literacy

- knowledge about health
- ability to find health information
- ability to interpret health information
- knowledge and ability to seek appropriate health care
- ability to understand and give consent
- ability to understand "risk"

The Big Picture

More work is needed to understand health literacy in the areas of policy, training, community development and communications. How much of the issue or solution is literacy? Where is literacy in the context of homelessness and unsafe housing?

Quote

"It sounds as though there is a lot of money spent on literacy. Really there isn't when you compare it to the size of the issue. If you think literacy is expensive, try ignorance."

Dorothy Silver,
Adult Learner

More research is needed on the impact of other aspects of society on health, including the following:

- Welfare policies
- Age
- Neighbourhood
- Income distribution
- Work situation
- Gender
- Race/Ethnic discrimination
- Literacy

Literacy, health and seniors*

Seniors are one of society's most vulnerable groups, especially when it comes to health literacy:

- 40% of seniors did not complete primary school and about 80% have some degree of low literacy.
- Many seniors have spent years developing skills that help them cope with low literacy. As a result, they often overestimate their literacy skills. At the same time, seniors with low literacy are very interested in their health; they want to be well enough informed to make their own decisions.
- Few seniors take part in literacy programs compared to the number who could benefit. The International Adult Literacy Survey (IALS) estimated that 8% of seniors were involved in literacy training. A literacy project in Regina found that only 10% of participants were well over 55.
- Seniors prefer to have someone their own age teach them literacy skills. With one-on-one tutoring, explanations can be personalized; one presenter described the best atmosphere as "intimate." In small groups, tutors have to allow enough time for discussion and group bonding.

**References:**

1. Owen Hughes. Working Plenary, May 29th. Canadian Public Health Association, *First Canadian Conference on Literacy and Health*. Ottawa. May 2000.
2. Rima Rudd. Health Literacy Research – Current Work and New Directions. (Workshop). Canadian Public Health Association, *First Canadian Conference on Literacy and Health*. Ottawa. May 2000.
3. Bruce Kappel. Literacy and Health into the Future – The Canadian and U.S. Experience. (Sub-plenary). Canadian Public Health Association, *First Canadian Conference on Literacy and Health*. Ottawa. May 2000.
4. Heather Fraser. Toward a Healthy Future – Second Report on the Health of Canadians: Literacy and Health Research, Policy and Program Implications. (Sub-plenary). Canadian Public Health Association, *First Canadian Conference on Literacy and Health*. Ottawa. May 2000.
5. Margot Kaszap and Jeannette Fortin. Perceptions des personnes âgées faibles-lecteurs en regard du système de santé. (Workshop). Canadian Public Health Association, *First Canadian Conference on Literacy and Health*. Ottawa. May 2000.
6. Sue Stableford. Literacy and Health into the Future – The Canadian and U.S. Experience. (Sub-plenary). Canadian Public Health Association, *First Canadian Conference on Literacy and Health*. Ottawa. May 2000.
7. Irving Rootman. Health Literacy Research – Current Work and New Directions. (Workshop). Canadian Public Health Association, *First Canadian Conference on Literacy and Health*. Ottawa. May 2000.
8. Laurie Ann McCardle, Diane Mullan. Low Literacy Seniors Needs – A Focus on Communities. (Workshop). Canadian Public Health Association, *First Canadian Conference on Literacy and Health*. Ottawa. May 2000.

Quote:

"I can't pronounce the names of my pills. I ask for them by their shape, size and colour."

The Learners' Wall

Theme 4: *Learning from learners***Overview**

Learners have expertise that needs to be used and shared. They need to be systemically involved at all stages in program and policy development – from basic concept through to delivery and evaluation. Literacy and health professionals owe it to learners to ensure they feel respected, involved and treated as people who do bring practical experience to the table.

At the conference, participants – many of whom were learners themselves – heard from learners who ranged from seniors and people from the North to people with developmental disabilities. Through the conference, learners shared their stories and offered insights into their experiences with the medical system. Many also wrote their stories on the "Learners' Wall," which served as a testament to their courage and determination.

Below, we have listed a variety of suggestions from learners related to health and literacy.

Drug labels and health forms

Packaging on no-name drugs can be a nightmare for people with low literacy skills. Learners often buy brand name drugs because they can recognize the colours and labels, even though they cost more. Generic and brand name drug companies should keep their products the same shape, colour and dosage.

Volunteers or staff can help learners in different ways. Volunteers can read questions on health forms to the learner. (Patients should carry their own case histories with them to make it easier to complete the forms.) Volunteers or nurse educators could also answer questions after patients have received instructions or other information.

The special needs of seniors

Seniors may not be able to follow their regimes because they cannot read the medication label, open the vials or keep track of dosing intervals. This results in more visits to the doctor, more lab tests, more medication and more stays in hospital or nursing homes.

Points to consider

As they package and market their products, pharmaceutical companies overlook the needs of people with low literacy skills. Different products are often packaged in similar ways, creating a lot of confusion. It also creates confusion when different pills come in the same sizes and shapes, or when manufacturers change the look of a familiar medication.

Problem

People count on finding a product in the same place every time they visit the store. They can get confused and frustrated if it is not there.

Solution

Keep products in the same place.

Problem

People with poor eyesight, especially seniors, have trouble reading medicine labels and expiry dates.

Solution

Medicine labels should be free of clutter. They should feature larger print and be stuck onto the bottle lengthwise so they are easier to read.

Problem

Written instructions can be confusing.

Solution

Pictographs could be used to show how to use a medication. Eyedrops, for example, could show a picture of an eye in the background.

Drugstores could play videos to show how to use medication.

Packaging and labelling checklist¹

- Does your company have a clear policy on the design of packaging that respects the needs of older consumers?
- Does the product clearly explain how to use it (including large print and illustrations)?

- Do the instructions include safety and hazard warnings?
- Are labels, instructions and warnings written in plain language?
- Have you focus-tested the labelling and instructions with senior consumers?
- Is the packaging easy to open?

Lessons from the North²

Conference participants learned about the need for clear verbal communication in Northern settings. Using the traditional native "talking stick," participants sat in a circle and shared their fears about being misunderstood. (Only the person holding the stick has the right to talk.) The exercise reminded people of how it feels to be misunderstood, and the importance of listening.

Through a skit that was based on a true story, participants witnessed an example of "miscommunication." In the skit, a native woman goes to a health clinic to get help for an earache. The nurse quickly "processes" the patient and prescribes some pills. A few days later, the patient returns with even greater pain in her ear. The nurse is even more rude until she learns the patient had put the pill in her ear.

In the discussion that followed, participants identified some issues raised by the skit:

- The nurse did not spend enough time with the patient. She did not explain the medical information, and treated the patient like a nuisance. She did not ask about any other health concerns.
- Any strategies to improve packaging and instructions must consider the context of the North. For instance, it may not be useful to say "take medication with meals." In the North, people may have only one or two meals a day, and they will not be evenly spaced. Pictographs of "sunrise" and "sunset" on a bottle may not be useful either since daylight hours vary a great deal throughout the year.

Participants suggested ways to improve packaging of medications for people in the North:

- Explain verbally that "take this pill before bedtime" refers to "big sleeps" and not "naps."
- Use uppercase and lowercase letters rather than all uppercase.
- Write the label sideways (vertically) so the person does not have to roll the pill bottle to read the words.
- Avoid writing "Take as directed" since the person may not remember the verbal instructions.
- Use coated paper for labels so the words do not rub off if the label gets wet.

Lessons from the developmentally handicapped

Developing plain language texts³

The Vocational Rehabilitation and Research Institute (VRRI) of Calgary, Alberta creates plain language documents for people with developmental disabilities. At the conference, VRRI gave some ideas about how to produce these documents. The key is to involve the clients in the process right from the start to "translate" the documents – adapting them from complex prose into plain language.

Step 1 Find people with developmental disabilities to participate

Talk to social service agencies about getting clients involved as "translators." Use "word of mouth" since people with developmental disabilities do not usually look at notice boards.

Step 2 Interview potential participants to become "translators"

During the interviews, look for people who can respect each other's abilities and be able to work on words together. Two to three people in a group are ideal. You will likely choose more women because men have more trouble admitting that they have low literacy skills.

Step 3 Create a plain language text**Tips for working with your group of "translators"**

- Highlight difficult words in bold and then define them.
- Work in the morning because minds are fresher.
- Since the work is tiring, only work for 1½ hours at a time.
- Do not ask translators if they "understand" the text. They may say "yes" to please you. It is always better to ask what a specific sentence or word means.
- Be prepared to listen to long stories. This is often how translators will explain the meaning of words or phrases to you.
- Be aware that some people in the group may understand a word or phrase and can explain it to others.
- If materials cannot be understood, remember that it is the fault of the materials, not the reader.
- Material relating to sexual abuse, discrimination and health problems can trigger an emotional response from your translators. For that reason, it is best to have separate translating groups for women and men. If women are triggered by the material, take a break and talk about it.

Tips for creating plain language texts

- Avoid "ING" endings.
- Do not hyphenate words over a line.
- Finish a sentence at the end of a line, if possible.
- Avoid contractions (like "don't").
- Use "someone" rather than "somebody."
- Take care with words such as "rights" since they can be confused with "right and left" or "right and wrong." Use the full term: "human rights."

- Strike a balance between being too general and too specific.
- Use a large, sans serif font such as Times Roman 13 or 14.
- Break down long sentences that include several ideas.
- Cut some words out.
- Add sub-heads and bullets.



Overcoming fears about writing

At a hands-on writing workshop called "Fearless Writing," conference participants had a chance to express their fears about writing and to learn ways to overcome those fears.

Common fears about writing

- My handwriting is messy.
- People will judge what I write.

The Captain's Log

- I may not use punctuation the right way.
- Teachers can be critical.
- Teachers working with deaf people have low expectations of their students.
- I'm afraid my writing won't be good enough.
- I may lose my train of thought.
- I skirt around big words.
- I speak in \$100 words and write in \$10 words.

Writing Exercises**Free Writing**

Participants are invited to write whatever they want for five minutes. They can ignore questions of spelling, grammar, etc. The idea is to free the writer inside to "create" without worrying about criticism.



Cloth Bag

Participants each reach into a cloth bag and pull out an object (a roll of surgical tape, a sucker, etc.). Each person then writes a few sentences to describe the item.

**References:**

1. Health Canada. Adapted from *Communicating with Seniors: Advice, Techniques and Tips*. Ottawa: Health Canada, Division of Aging and Seniors. 1999.
2. Wonda Bradley, Liesel Briggs and Joy Coldwell. "I'm not better, nurse" – Northern Experiences of Health Literacy. (Workshop). Canadian Public Health Association, *First Canadian Conference on Literacy and Health*. Ottawa. May 2000.
3. Sandra Cormier and Janet Pringle. Working with Developmentally Disabled People – Producing Low-level Literacy Materials. (Workshop). Canadian Public Health Association, *First Canadian Conference on Literacy and Health*. Ottawa. May 2000.

Theme 5: *Building literacy and health partnerships*

Overview

Just as communication requires at least two active participants, literacy programs also thrive on different kinds of partnerships.

On an organizational level, partnerships within the community allow literacy and health professionals to share ideas and resources, leverage funds and expand networks. Conference participants heard about the experiences of Action ABC, a non-profit group that provides bilingual literacy education to people recovering from substance abuse. It has established partnerships with several hospitals in Montreal and Toronto that offer treatment for substance abuse. Other examples of community-based partnerships include the Saskatchewan Literacy Network and Frontier College.

On a program level, partnerships between organizations and people with low literacy skills ensure that the expertise and experience of learners is heard and respected. Below, the *Captain's Log* features highlights of partnerships with youth such as TeenNet and What the HEALTH!, as well as partnerships with seniors.

Finally, the conference noted the importance of establishing partnerships across national borders. American participants, for example, held up CPHA's National Health and Literacy Program as a model for partnership among different sectors. A U.S. - Canadian literacy and health partnership would help both countries boost the profile of literacy and health.

Partnerships with Youth

TeenNet

TeenNet, set up in 1995, is a Web site that promotes health among at-risk youth. It has four goals:

- to produce practical tools
- to help youth identify and express their health needs
- to enhance control over personal health and support
- to generate new knowledge

There is no shortage of information on the Internet. The challenge for teens is to find what they want, and to make sense of it. To address this problem, TeenNet has a component called "Teen Clinic Online." It provides links to information on the Internet and shows teens how to evaluate the information.

TeenNet's partners include community-based organizations that deal with adolescents and/or health issues, and Frontier College (see page 48).

How to consult with youth partners

- Leave your assumptions behind.
- Be ready to listen.
- If you are telling people that they are the experts, you have to keep the promise. Do not go into a situation with expectations of what you will find.
- Pay fair value for your partners' time. If you tell people their opinions are valuable, you should pay them for their time.
- Follow through and report back. Some youth have been "focus grouped to death." It is important to follow through on your promises and be sure to get back to them with the results of your research.

What the HEALTH!

In May 2000, as part of its "Developing a Health-Literacy Curriculum for At-risk Youth" project, CPHA produced a resource kit called "What the HEALTH!" The kit was produced with the active participation of youth currently enrolled in literacy programs offered by Frontier College, street youth, youth in school, health professionals and literacy practitioners. CPHA spent six hours with groups of youth in five Canadian cities. After discussing issues related to health and literacy (housing, unemployment, etc.), the youth wrote "news stories" about what they considered to be the Top 10 issues. Each "story" is designed to stimulate more discussion.

What the HEALTH! is one example of CPHA's National Literacy and Health Program in action. The program began in 1992. By 1994 it

Quote

"We are all just one bad choice from being at risk."

Promoting Health
Among Youth At-risk
workshop

had 10 national partners. Today, it has working relationships with 26 national health associations. It also works closely with numerous federal government departments.

Partnerships with Seniors

The Seniors Education Centre

The Seniors Education Centre is a partnership between the Seniors' University Group Inc. and University Extension, University of Regina. The Centre, founded in 1977, provides more than 100 education programs for older adults every year. The Centre also conducts applied research and community development work in areas affecting older adults:

- literacy
- abuse prevention
- health promotion
- caregiving
- cross-cultural/intergenerational communities
- learning technology
- distance education issues

Community-Based Partnerships

Frontier College

Since 1899, Frontier College has been teaching Canadians to read and write. The College reaches out to people wherever they are and responds to their individual needs. Using an approach called Student Centred Individualized Learning (SCIL), the College creates individual programs based on students' strengths and experience. The College has specific programs targeted at inmates, street youth, teens, adults and other groups.

In 1988-89, Frontier College began working with the Ontario Public Health Association to get literacy and health on the agenda. This

partnership enabled the two organizations to access two levels of federal funding and one source at the provincial level. The partnership extended to all levels of government, literacy students, literacy staff, public health nurses, doctors and pharmacists. The high level of collaboration allowed them to field test materials with intended recipients, create opportunities for health care workers to learn about literacy in all its dimensions, and enable literacy workers to learn about health care.

The landmark study, "Literacy and Health Project: Making the World Healthier and Safer for People Who Can't Read," produced by OPHA/Frontier College paved the way for the creation of CPHA's National Literacy and Health Program.

Action ABC

Action ABC is a non-profit charity with a national mandate to provide bilingual literacy education to people recovering from substance abuse. The organization provides literacy education at several hospitals and shelters in Montreal and Toronto which offer treatment for substance abuse:

- The Jewish General Hospital's Methadone Program
- The Montreal General Hospital's Addiction Unit
- "Crossroads" at the Douglas Hospital
- Centre de Recherche et d'aide pour Narcomanes
- The Centre for Addiction and Mental Health (Toronto)

The program tracked 120 students to see if they improved their level of literacy. It also looked at other key indicators such as employment status, marital status, form of substance abuse and gender. Here are some of the conclusions:

- People who had jobs progressed in higher numbers than those without jobs.
- Married students and single women who have boyfriends progress to higher literacy levels.

- Almost twice as many females progressed two literacy levels than males.
- A criminal record hinders progress.

Action ABC is speaking with substance abuse rehabilitation centres across Canada to make front-line literacy service more available. It is also conducting clinical research to see if literacy training helps individuals who are recovering from substance abuse to re-integrate into society.

Saskatchewan Literacy Network

The Saskatchewan Literacy Network promotes literacy and health in several ways. For instance, the Network has published a study showing the links between health system use and low education levels. It has also produced a kit that shows how low literacy skills affect health. Finally, it offers plain language workshops for healthcare workers. Participants at these workshops have offered comments such as these:

"It increased my awareness of the literacy issues facing people and how that related to my communication with them."

"It gave useful tips on clear writing, focusing on information and design."

"All staff should take this workshop."

Canada-U.S. Partnerships

At the sub-plenary, "Literacy and Health into the Future – the Canada and U.S. Experience," participants identified the need to develop Canadian and American partnerships. American participants made it clear that they hold up CPHA's National Literacy and Health Program as a model to raise awareness and to explore issues related to health and literacy and build partnerships. In addition to funding available from the National Literacy Secretariat, literacy partnerships in Canada provide an infrastructure for literacy and health programs and services both provincially and nationally.

The private sector in the United States does provide money for research into literacy and health. However, American participants noted they still face the challenge of finding stable resources to support a national initiative on literacy and health. Forging a U.S. - Canadian literacy and health partnership would provide both parties with information, potential in-kind resources and contacts to boost the profile of literacy and health in both countries.



-
- *This approach is consistent with an adult basic education model which focuses on learning materials relevant to a learner's own life and experience. This model can also be adapted into other programs, e.g., life skills, vocational training.*

Conclusion

The First Canadian Conference on Literacy and Health, *Charting the Course for Literacy and Health in the New Millennium*, brought together individuals from a vast array of health disciplines and other sectors in an effort to build and strengthen literacy and health partnerships as well as position literacy as a critical health issue.

For many participants, the conference introduced them to new ideas and broadened their understanding of the health impacts of low literacy. For others, who have worked in the literacy and health field, the conference provided them with new ways of looking at old challenges. Either way, the conference reinforced their commitment to working on an issue that affects all Canadians.

People with low literacy skills may not understand health information a health professional gives them to read. They may not understand what a health professional tells them. Barriers to the health services they require to be healthy are numerous and overwhelming. Often, people with low literacy skills may not use health services, except in emergency situations.

The conference addressed the very immediate problem of access to the health information and services that low-literacy health consumers require to be healthy. But it went further than that.

It also explored the specific challenges that people who have low literacy skills and disabilities and/or cultural differences face in accessing the health services they need.

New techniques in plain language and clear verbal communication skills training along with literacy testing tools were introduced and discussed in numerous workshops. Health professionals were introduced to ways in which plain language and clear verbal communication could form the basis of a prevention strategy for their professional liability. Current case law as it pertains to informed consent and plain language was presented and discussed at length during the proceedings.

Literacy and health research in both the United States and Canada was presented, gaps were identified, and the seeds for new research projects were planted throughout the conference.

One of the greatest strengths of the conference – which many participants made a point of sharing with us – was the involvement of adult learners from both Canada and the United States in a meaningful way throughout the event. In addition to sharing their stories on the Learners' Wall, adult learners took part in the conference as presenters and speakers. Many learners told us that the conference respected and valued their expertise.

Also, the Weiler Award made a significant contribution to the proceedings. Formally recognizing individuals and organizations who/that have made substantial contributions to the literacy and health field provided support and encouragement not only to the award recipients, but also to all those who attended the conference and whose efforts in the literacy and health field are often not recognized.

This first conference is no doubt a stone laid on the path forged by the Canadian Public Health Association's National Literacy and Health Program over nine years ago. It has allowed us to reflect upon our accomplishments, but also to identify the work we have yet to do in this field. And there is much. Ultimately, it has helped the National Literacy and Health Program to map out its role in the years ahead. For this, CPHA is grateful to all those who participated in the conference.

Quote

"More than ever, our voices must be persistent and compelling in order to keep literacy high up on the crowded agenda that faces our nation and the world as we set our course in this century."

Senator Joyce Fairbairn,
P.C.

APPENDIX 1

Conference Presenters

Andrew Aitkens

Project Coordinator
Medication Packaging & Labelling Project
Canadian Public Health Association
400-1565 Carling Avenue
Ottawa, ON K1Z 8R1

Marin P. Allen

Chief, Office of Health Communication &
Public Liaison
National Institutes on Deafness &
Other Communication Disorders
National Institutes of Health
31 Center Drive, MSC 2320
Bethesda, MD 20892-2320, USA

Francine Beauregard

Manager, Information Coordination &
Dissemination
Division of Aging & Seniors
Health Canada
PL 1908A1 - Jeanne Mance Bldg.
Tunney's Pasture
Ottawa, ON K1A 1B4

Michelle A. Black

Writer/Communications Consultant
Resource Development Team
Canadian Health Network
84 Lundt St.
Richmond Hill, ON L4C 5V9

Anne Bouillon

Diététiste de la santé publique
Service de la santé de la Région
d'Ottawa-Carleton
495, chemin Richmond, 3e étage
Ottawa, ON K2A 4A4

Wonda Bradley

Nurse in Charge
Pelly Crossing Health Centre
Pelly Crossing, YT Y0B 1P0

Sharon Brez

Clinical Nurse Specialist
Civic Campus, The Ottawa Hospital
1053 Carling Avenue - "A6"
Ottawa, ON K2A 0P7

Liesel Briggs

Executive Director
Yukon Learn
308 Hanson Street
Whitehorse, YT Y1A 1Y6

Elaine Cairns

Consultant, Literacy &
Parenting Skills Program
Further Education Society of Alberta
Bow Valley College
642-332 6 Avenue SE
Calgary, AB T2G 4S6

Lorette Chiasson

Agente de projet
Base de données en alphabétisation des
adultes (BDAA)
703 rue Brunswick, Maison Scovil
Fredericton, NB E3B 1H8

Shawn Chirrey

CHN Youth Affiliate Coordinator
Department of Public Health Sciences
University of Toronto
12 Queen's Park Cres. West
McMurrich Building, 9A
Toronto, ON M5S 1A8

Joy Coldwell

Learner Rep
Yukon Learn
308 Hanson Street
Whitehorse, YT Y1A 1Y6

Sandra Cormier

Plain Language Translator
Research Department
Vocational Rehabilitation
Research Institute
304 - 33rd Street NW
Calgary, AB T2L 2A6

Gordon DeWolfe

Chair, Learners' Advisory Network
Movement for Canadian Literacy
21 Apple Dr., RR #6
Truro, NS B2N 5B4

Appendix 1 - Conference Presenters**Cecilia Doak**

Director of Education
Patient Learning Associates Inc.
4 Chilham Court
Potomac, MD 20854-6144 USA

Leonard G. Doak

President
Patient Learning Association Inc.
4 Chilham Court
Potomac, MD 20854-6144 USA

Sucy Eapen

Project Coordinator
Canadian Ethnocultural Council
176 Gloucester Street, Suite 400
Ottawa, ON K2P 0A6

Senator Joyce Fairbairn, P.C.

Special Advisor for Literacy
Room 571-S, Centre Block
Senate of Canada
Ottawa, ON K1A 0A4

Louise Ford

Executive Director
Ottawa Deaf Centre
310 Elmgrove Avenue
Ottawa, ON K1Z 6V1

Nancy Foreman

Project Coordinator
Youth Literacy and Health
Canadian Public Health Association
400-1565 Carling Avenue
Ottawa, ON K1Z 8R1

Jeannette Fortin

Infirmière, professionnelle de recherche
Groupe de recherche interuniversitaire
Alpha-Santé
Université Laval
4782 Escoffier
Cap-Rouge, QC G1Y 3J5

Heather Fraser

Strategic Policy Manager
Major Projects Directorate
Health Canada
304-1155 West Pender Street
Vancouver, BC B6E 2P4

Priscilla George

Aboriginal Literacy Consultant
National Aboriginal Design Committee
Ningwakwe Consulting
26 Carluke Crescent #409
Toronto, ON M2L 2J2

Carolena Gordon

Avocat
Nicholl Paskell-Mede
830-2000 rue Peel
Montréal, QC H3A 2W5

Deborah Gordon-El-Bihbety

Director, National Projects
Canadian Public Health Association
400-1565 Carling Avenue
Ottawa, ON K1Z 8R1

Theresa Harper

Patient Education Specialist
Education & Development
Hamilton Health Sciences Corporation
3V51 McMaster Campus, 1200 Main Street West
Hamilton, ON L8N 3Z5

John Hastings

Past President
Canadian Public Health Association
400-1565 Carling Avenue
Ottawa, ON K1Z 8R1

Marcia Drew Hohn

Director of Northeast SABES
System for Adult Basic Education Support
NECC
45 Franklin Street
Lawrence, MA 01840, USA

Peter S. Houts

Research Associate
Family & Patient Services
Johns Hopkins Oncology Center
70 Hillymede Road
Hummelstown, PA 17036, USA

Owen Hughes

Chief, Division of Maternal & Newborn Care
Ottawa Hospital
1105 Carling Avenue
Ottawa, ON K1Y 4G5

Debra Huron

Manager, Plain Language Services
Canadian Public Health Association
400-1565 Carling Avenue
Ottawa, ON K1Z 8R1

Robert E. Johnson

Professor, Department of ASL, Linguistics
and Interpretation
Gallaudet University
800 Florida Avenue NE
Washington, DC 20002-3695 USA

Bruce Kappel

Kappel Consulting
3 Ashgrove Place
Toronto, ON M3B 2Y9

Margot Kaszap

Professeure et chercheure à la FSE, Ph.D.
en didactique
Groupe de recherche interuniversitaire
Alpha-Santé
Université Laval
Bureau 866, tour des Sciences de l'Éducation
Ste-Foy, QC G1K 7P4

Jann Allison Keenan

President
The Keenan Group, Inc.
9862 Century Drive
Ellicott City, MD 21042, USA

Kristen M. Kilker

Research Analyst
National Academy on an Aging Society
1030 - 15th Street N.W., Suite 250
Washington, DC 20005-1503, USA

Alice Kneeland

Student, Write to Learn Project
206-4917 - 50 Avenue
Camrose, AB T4V 0S2

Philip Knight

Adj. Professor, Faculty of Law
University of British Columbia
1074 Fulton Avenue W.
Vancouver, BC V7T 1N2

Luce Lapierre

Directrice
Fédération canadienne pour
l'alphabétisation en français (FCAF)
235, chemin de Montréal, bureau 205
Vanier, ON K1L 6C7

Marthe Lavoie

Infirmière en santé publique
Service de la santé de la Région
d'Ottawa-Carleton
495, rue Richmond, 3e étage
Ottawa, ON K2A 4A4

Margaret Lerhe

Manager of Education
Ottawa Regional Cancer Centre
501 Smyth Road
Ottawa, ON K1G 2X8

Jeri A. Levesque

Associate Professor, Programs Evaluator
Webster University/Lift-Missouri
42 Lake Forest Lane
St. Charles, MO 63301 USA

Norma Levitt

Member, Senior Wellness Group
South Riverdale Community Health Centre
32 Rushbrooke Avenue
Toronto, ON M4M 3A9

Al Levitt

Member, Senior Wellness Group
South Riverdale Community Health Centre
32 Rushbrooke Avenue
Toronto, ON M4M 3A9

Lisa Lucas

Executive Director
Action ABC Inc.
500 Clarke Avenue
Westmount, QC H3X 2E1

Laureen MacKenzie

Consultant, Literacy & Parenting
Skills Program
Further Education Society of Alberta
Bow Valley College
642-332 - 6 Avenue S.E.
Calgary, AB T2G 4S6

Appendix 1 - Conference Presenters**John Madison**

Associate Professor, Department of English
National Technical Institute for the Deaf
52 Lomb Memorial Drive
Rochester, NY 14623-5604 USA

Lynda Magerl

Saskatchewan Literacy Network
160 - 4th Avenue S.E.
Swift Current, SK S9H 3L4

George Maher

Plain English Campaign
PO Box 3, New Mills
High Peak SK22 4QP, England

Oonagh Maley

TeenNet Project Coordinator
Department of Public Health Sciences
University of Toronto
12 Queen's Park Cres. West
McMurrich Building, 9B
Toronto, ON M5R 2X9

Laurie Ann McCordle

Executive Director.
Women's Network P.E.I.
PO Box 233
Charlottetown, PEI C1A 7K4

Barbara McTavish

Student, Write to Learn Project
206-4917 50 Avenue
Camrose, AB T4V 0S2

Cathy D. Meade

Director, Education Program/Associate
Professor
H. Lee Moffitt Cancer Center and
Research Institute
12902 Magnolia Drive
Tampa, FL 33612, USA

Wendy Mettger

President
Mettger Communications
129 Grant Avenue
Takoma Park, MD 20912, USA

Diane Mullan

Literacy Program Coordinator
University of Regina Extension
Seniors' Education Centre, Room 106,
Gallery Building
College Avenue & Cornwall Street
Regina, SK S4S 0A2

T. Scott Murray

Director
Culture, Tourism & The Center for
Education Statistics
Statistics Canada
R.H. Coats Building, Tunney's Pasture,
Ottawa, ON K1A 0T6

John Daniel O'Leary

President
Frontier College
35 Jackes Avenue
Toronto, ON M4T 1E2

Elsie Petch

Health Promoter
South Riverdale Community Health Centre
955 Queen Street East
Toronto, ON M4M 3P3

Kathy Plomer

Health Educator, MPH
AMC Cancer Research Center
1600 Pierce Street
Denver, CO 80020, USA

Diane Pouliot

Agente de projet et de liaison
Fédération canadienne pour
l'alphabétisation en français
235, chemin Montréal, pièce 205
Vanier, ON K1L 6C7

Barry Power

Pharmacy Consultant, Medical Services Branch
Health Canada
Jeanne Mance Bldg., Room 2076D
AL 1920D, Tunney's Pasture
Ottawa, ON K1A 0L3

Janet Pringle

Researcher, Research Department
Vocational & Rehabilitation Research Institute
3304-33rd Street NW
Calgary, AB T2L 2A6

Charles Ramsey

Executive Director
National Adult Literacy Database (NALD)
703 Brunswick Street, Scovil House
Fredericton, NB E3B 1H8

Leonard M. Reyno

Regional Consultant
The Bayer Institute for Health Care
Communication
Nova Scotia Cancer Centre
QEII Health Sciences Centre
5820 University Avenue
Halifax, NS B3H 1V7

Ana Reynoso

Student Action Health Team
48 New Park Street, #3
Lynn, MA 01905, USA

Elsa Reynoso

Student Action Health Team
91 Green St.
Lynn, MA 01902, USA

Audrey Riffenburgh

President
Riffenburgh & Associates - Specialists in Plain
English & Readability
1606 Central Avenue S.E., Suite 201
Albuquerque, NM 87106, USA

Paul Roberts

Senior Research Associate
Canadian Council on Social Development
441 MacLaren, 4th Floor
Ottawa, ON K2P 2H3

Irving Rootman

Director, Centre for Health Promotion
University of Toronto
100 College Street, Suite 207
Toronto, ON M4G 1L5

Joel Rosenbloom

Coordinator, Dental Services
Queen West Community Health Centre
168 Bathurst Street
Toronto, ON M5V 2R4

Rima E. Rudd

Lecturer in Health Education
Department of Health and Social Behavior
Harvard School of Public Health
677 Huntington Avenue
Boston, MA 02115, USA

Rob Sarginson

Regional Coordinator
Literacy Partners of Manitoba
RR#3, Box 68, Group 349
Selkirk, MB R1A 2A8

Joanne G. Schwartzberg

Director, Aging and Community Health
American Medical Association
515 North State Street
Chicago, IL 60610, USA

Linda Shohet

Director
The Centre for Literacy
3040 Sherbrooke Street West, Suite 4BI.6
Montreal, QC H3Z 1A4

Dorothy Silver

Founder, Second Chance Learners
18 Ross Terrace
Fredericton, NB E3A 8E4

Sue Stableford

Director, Maine AHEC Health Literacy Center
University of New England
11 Hills Beach Road
Biddeford, ME 04005, USA

Nayda Veeman

Executive Director
Saskatchewan Literacy Network
206-220 - 3rd Avenue South
Saskatoon, SK S7K 1M1

John Wild

Plain English Campaign
PO Box 3, New Mills,
High Peak SK22 4QP England

APPENDIX 2

Resources on Literacy and Health

Audio-Visuals:

Acadia Health Education Coalition. (Producer). Face to Face. Hallowell, Maine: Producer, 1993.

Alberta Association for Adult Literacy. (Producer) The Literacy Audit Kit. (Manual and Video). Calgary: Producer, 1998.

American Medical Association. (Producer). Low Health Literacy: You Can't Tell by Looking. Part of the Health Literacy Introductory Kit. Chicago: Producer, 2000.

Frontier College. (Producer). The Clear Writer's Hit Squad. Toronto: Producer, 1991.

Ottawa Deaf Centre. (Producer). Communicating with Deaf Patients. Ottawa: Producer, 2000.

Rudd, R. & DeJong, W., Harvard School of Public Health, Department of Health and Social Behavior. (Producer). In Plain Language. Boston, Massachusetts: Producer, 2000.

The Literacy Project, Inc. (Producer). Together We Bloom: Women Speaking Out Against Violence. Greenfield, MA: Producer, 1998.

Documents:

AMC Cancer Research Center. Beyond the Brochure: Alternative Approaches to Effective Health Communication. Denver: Centers for Disease Control and Prevention, 1994.

Baldwin, R. Clear Writing and Literacy. Toronto: Ontario Literacy Coalition, 1990.

Breen, M. Partners in Practice: The Literacy and Health Project, Phase Two, August 1990 – October 1992: Summary Report. Toronto: Ontario Public Health Association, 1993.

Brez, S.M. Assessing literacy for patient teaching: perspectives of adults with low literacy skills. Journal of Advanced Nursing, 25, (1997): 1040-1047.

Canadian Public Health Association and Health Canada. Building a Healthy Future. Canadian Journal of Public Health, Vol. 91, No. 2, 11-116. Ottawa: CPHA, 2000.

Canadian Public Health Association. Creating Plain Language Forms for Seniors: A Guide for the Public, Private and Not-for-Profit Sectors. Ottawa: Author, 1998.

Appendix 2 - Resources on Literacy and Health

Canadian Public Health Association. Directory of Plain Language Health Information. Ottawa: Author, 1999.

Canadian Public Health Association. Easy Does It! Plain Language and Clear Verbal Communication Training Manual. Ottawa: Author, 1998.

Canadian Public Health Association. What the HEALTH! A Literacy and Health Resource for Youth. Ottawa: Author, 2000.

Canadian Public Health Association. Working with Low-literacy Seniors: Practical Strategies for Health Providers. Ottawa: Author, 1998.

Centre for Literacy. Health, Communication and Literacy: An Annotated Bibliography. Montreal: Author, 1998.

Doak, C., Doak, L., & Root, J. Teaching Patients with Low Literacy Skills, Second Edition. Philadelphia: Lippincott Co., 1996.

Eapen, S. Use and Misuse of Drugs by Seniors: A Cross-Cultural Education Model. Ottawa: Canadian Ethnocultural Council, 2000.

Health Canada. Communicating with Seniors: Advice, Techniques and Tips. Ottawa: Division of Aging and Seniors, Health Canada, 1999.

Health Canada, Statistics Canada and the Canadian Institute for Health Information. Toward a Healthy Future: Second Report on the Health of Canadians. Ottawa: Health Canada, 1999.

Health Canada. Medication Matters - How You Can Help Seniors Use Medication Safely. Ottawa: Division of Aging and Seniors, Health Canada, 1997.

Hohn, M.D. Empowerment Health Education in Adult Literacy: A Guide for Public Health and Adult Literacy Practitioners, Policy Makers and Funders. Literacy Leader Fellowship Program Reports: Vol. III, No. 4, Part A. Washington, D.C.: National Institute for Literacy, 1998.

Kurtz, S., Silverman, J. & Draper, J. Teaching and Learning Communication Skills in Medicine. Oxon, UK: Radcliffe Medical Press, Ltd, 1998.

Meade, C.D. & Smith, C.F. Readability Formulas: Cautions and Criteria, Patient Education and Counseling. Oncology Nursing Forum, 17 (1991): 153-158.

National Literacy Secretariat. Plain Language, Clear and Simple. Ottawa: Minister of Supply and Services Canada, 1991.

Norton, M. & Campbell, P. Learning for Our Health: A Resource Book for Participatory Literacy and Health Education. Edmonton: The Learning Centre Literacy Association, 1998.

Ontario Public Health Association and Frontier College. The Literacy and Health Project. Phase One: Making the World Healthier and Safer for People Who Can't Read. Toronto: Ontario Public Health Association, 1989.

Organisation for Economic Co-Operation and Development and Statistics Canada. Literacy in the Information Age: Final Report of the International Adult Literacy Survey. Ottawa: Statistics Canada, 2000.

Perrin, B. How Does Literacy Affect the Health of Canadians? A Profile Paper. Ottawa: Policy Development & Coordination Division, Health Promotion and Programs Branch, Health Canada, 1998.

Petch, E. Wise Use of Medications: A Health Promotion Approach to Community Programming for Safe Medication Use With and For Seniors. Toronto: South Riverdale Community Health Centre, 1992.

Roberts, P. & Fawcett, G. At Risk: A Socioeconomic Analysis of Health and Literacy Among Seniors. Ottawa: Statistics Canada, 1998.

Roter, D. & Hall J. Doctors Talking with Patients/Patients Talking with Doctors. Westport, Connecticut: Auburn House, 1992.

Rudd, R. E., Colton, T., & Schacht, R. An Overview of Medical and Public Health Literature Addressing Literacy Issues: An Annotated Bibliography. Cambridge, MA: The National Centre for the Study of Adult Learning and Literacy (NCSALL), January 2000, Report #14.

Sarginson, R. Literacy and Health: A Manitoba Perspective. Winnipeg: Literacy Partners of Manitoba, 1997.

Saskatchewan Literacy Network. Health and Literacy: How Do They Relate? Saskatoon: Author.

Seniors Education Centre. Saskatchewan Older Adult Literacy Survey: Final Report. Saskatchewan: University of Regina, University Extension, 1992.

Statistics Canada. Literacy, Economy and Society: Results of the First International Adult Literacy Survey. Ottawa: Author, 1995.

Statistics Canada. Reading the Future: A Portrait of Literacy in Canada. Ottawa: Author, 1996.

World Education and National Institute for Literacy. Health and Literacy Compendium: An annotated bibliography of print and Web-based health materials for use with limited-literacy adults. Boston: Health and Literacy Initiative, World Education, 1999.

Appendix 2 - Resources on Literacy and Health**Web sites:**

- <http://www.alphaplus.ca>
Centre AlphaPlus Center
- <http://www.bccpd.bc.ca/wdi>
The Wellness and Disability Initiative (WDI) Resource Centre
- <http://www.canadian-health-network.ca>
Canadian Health Network (CHN)
- <http://www.consumer.ca>
Consumers' Association of Canada
- <http://www.literacynet.org/value>
Voice for Adult Literacy United for Education (VALUE)
- <http://www.nald.ca>
National Adult Literacy Database Inc. (NALD)
- <http://www.nifl.gov/lincs>
Literacy Information and Communications System (LINCS)
National Institute for Literacy
- <http://www.nlhp.cpha.ca>
National Literacy and Health Program (NLHP)
Canadian Public Health Association
- <http://www.plainenglish.co.uk>
Plain English Campaign
- <http://www.pls.cpha.ca>
Plain Language Service (PLS), Canadian Public Health Association
- <http://www.prenataled.com/healthlit/default.asp>
Health Literacy Toolbox
- <http://www.sabes.org/health/index.htm>
System for Adult Basic Education Support (SABES)
- <http://www.teennetproject.org>
TeenNet: Engaging Teens in Health Promotion Using Information
Technology
- <http://www.une.edu/com/othrdept/hlit/index.htm>
Maine AHEC Health Literacy Center
- <http://www.worlded.org/us/health/lincs/>
National Institute for Literacy, Health and Literacy Special Collection

Canadian Public Health Association

The Canadian Public Health Association (CPHA) is a national, independent, not-for-profit voluntary association representing public health in Canada with links to the international public health community. CPHA's mission is to constitute a special national resource in Canada that advocates for the improvement and maintenance of personal and community health according to the public health principles of disease prevention, health promotion and protection, and healthy public policy.

National Literacy and Health Program

The National Literacy and Health Program (NLHP) is a partnership of 27 national health associations working to raise awareness among Canadian health professionals about the links between literacy and health. The NLHP provides health professionals with resources designed to help them serve people with low literacy skills more effectively. The NLHP's Plain Language Service supports improved health communication by offering plain language revisions, assessments and workshops to health organizations in the public, not-for-profit and private sectors.

National Literacy and Health Program Partners

Canada's Research-Based Pharmaceutical Companies, Canadian Association for Community Care, Canadian Association of Occupational Therapists, Canadian Association of Optometrists, Canadian Association of Social Workers, Canadian Centre on Substance Abuse, Canadian College of Health Service Executives, Canadian Dental Assistants Association, Canadian Dental Association, Canadian Dental Hygienists Association, Canadian Healthcare Association, Canadian Institute of Child Health, Canadian Medical Association, Canadian Nurses Association, Canadian Paediatric Society, Canadian Palliative Care Association, Canadian Pharmacists Association, Canadian Physiotherapy Association, Canadian Psychiatric Association, Canadian Public Health Association, Catholic Health Association of Canada, College of Family Physicians of Canada, Dietitians of Canada, Institute of Palliative Care, Nonprescription Drug Manufacturers Association of Canada, Society of Obstetricians and Gynaecologists of Canada, Victorian Order of Nurses.